

## § 5 Surveillance and Screening

### § 5.1 Preamble

Although attention to developmental disabilities should be a central component of developmental monitoring for all children,<sup>4,140,156</sup> fewer than 30 per cent of primary care providers conduct routine surveillance/screening.<sup>56,79,25</sup> Numerous studies have established that parental concerns about communication, development and behaviour are highly sensitive and specific and should always receive serious consideration.<sup>77,81,82,84</sup> By contrast, absence of parental concerns has only modest specificity in detecting normal development.<sup>77</sup> Therefore, active surveillance may detect children with developmental disorders at the earliest possible time. As well, surveillance and screening must be seen not as one-time events, but rather ongoing efforts repeated at various ages.<sup>140,6</sup>

It is critical that children with ASD be identified as early as possible. It is possible to identify and diagnose ASD by three years of age and some believe as early as the second year of life.<sup>119,121,179,37,45,127,19,140,261,262</sup> Studies have demonstrated that most parents of children subsequently diagnosed with ASD first became concerned about their child's development around 18 months of age.<sup>96,97</sup> However, research on surveillance and screening for ASD is at a very early stage. Both the process and tools used for the purpose of detecting previously unidentified cases of ASD continues to be unsettled.<sup>25,90,56</sup>

Presently available screening instruments and known prevalence rates of ASD do not support general population-wide screening.<sup>140,56,246</sup> No single instrument has yet been shown to have the ideal balance of sensitivity and specificity required for the purpose of general screening.<sup>246</sup> Some instruments have shown promise, but only within a narrow age range (e.g. the Checklist for Autism in Toddlers (CHAT) at around 18 months, although even then the sensitivity is not adequate). As well, current methods of screening for ASD may not identify children under 18 months of age, or those with milder or atypical presentations.<sup>64</sup> Overall, the psychometric properties of ASD-specific screening instruments has not been adequately established, particularly for community-based settings.

Selective screening is defined as the use of specific methods and instruments with sub-groups of children identified to be at higher risk for ASD. This would include all children for whom there is clinical suspicion of an ASD, including those who fail general developmental surveillance. It would also include siblings of children with ASD, who have an occurrence risk of 10 to 20 per cent (or approximately 50 times the population baseline risk).<sup>64,230,231,232,233,234,15,159,173,246</sup> At present, there is insufficient evidence to recommend any single procedure to screen for ASD in all children suspected of an ASD in the primary care setting.<sup>56</sup> Therefore screening instruments may be seen as practice options, as a means of further data-gathering or clarification of the clinical situation. "Failing" or "passing" on any single measure should not be the sole determinant of whether or not a child is referred for further assessment.

### § 5.2 Practice Standards

- A) Earliest possible identification of ASD requires an ongoing process of general developmental surveillance of all children with specific focus on social-communication delays and deficits.<sup>4,6,64,246,140,90,95</sup>

- B) General developmental surveillance for ASD is conducted by all primary care practitioners. It can include any or all of the following components: <sup>140,107,56</sup>
- i) serious consideration of all voiced parental concerns about communication, development and behaviour; <sup>77,81,82,84</sup>
  - ii) administration of general developmental screening instruments (see Section 5.3.A);
  - iii) particular attention to developmental milestones related to communication and reciprocal social interaction, two areas central in ASD (See Appendix 1); and, <sup>107,140,249</sup>
  - iv) Ongoing monitoring for the presence of “clinical clues” or “red flags” of ASD at each contact with the child and parents, including scheduled “well-child” visits (See Appendix 2). <sup>246,140,168,251,145,114,22</sup>
- C) Selective ASD screening should be considered by all primary care practitioners as a means of clarifying the clinical presentation or gathering further data whenever a child is suspected of, or at higher risk for an ASD. It includes either or both of the following: <sup>140</sup>
- i) administration of age-appropriate ASD-specific screening instrument(s) (See Section 5.3(c)); and,
  - ii) review of ASD screening questions with caregiver(s) (See Appendix 3).
- D) Siblings of children with all developmental disabilities and psychiatric syndromes (including, but not limited to ASD) should be carefully monitored not only for ASD-related symptoms but also for language delays, learning difficulties, social problems, and anxiety or depressive symptoms. <sup>64</sup>

## § 5.3 Clinical Practice Guidelines

- A) A number of standardized and norm-referenced general developmental screening instruments are available for primary care practitioners. Recommended developmental screening tools include: <sup>(b)</sup>  
<sup>63,64</sup>
- i) The Parents’ Evaluations of Developmental Status; <sup>83</sup>
  - ii) The Ages and Stages Questionnaire; <sup>30</sup>
  - iii) Ages and Stages Questionnaire: Social Emotional; <sup>282</sup>
  - iv) The BRIGANCE Screens; and, <sup>266,267,268</sup>
  - v) The Child Development Inventories. <sup>100</sup>
- B) The following recommendations for general developmental surveillance should be seen as practice options for all primary care physicians in British Columbia: <sup>4,90</sup>
- i) combining parental concern with a standardized parental report form is an effective means for early behavioural and developmental screening in the primary care setting; <sup>84</sup>
  - ii) periodic health examinations by general medical practitioners provide specific opportunities for routine developmental surveillance in young children; and, <sup>140</sup>
  - iii) the periodic exams at 15, 18, and 24 months may be particularly important since there is often evidence of ASD prior to the child’s third birthday. <sup>140</sup>

- C) Selective ASD Screening with a child who is suspected of, or at higher risk for, having an ASD may assist in clarifying the clinical situation or gathering more data. If a screening instrument is used, it is important to make certain that it has been validated by research, and is designed for the age of the child. The following practice options may be used as intended and with requisite cautions by primary care practitioners in British Columbia<sup>(c)</sup>:<sup>140,141</sup>
- i) the Checklist for Autism in Toddlers (CHAT)<sup>18,20,44,250,251</sup> or the Modified Checklist for Autism in Toddlers (M-CHAT),<sup>155</sup> for children at or near 18 months of age (chronologically);
  - ii) the Screening Test for Autism in Two-Year-Olds (STAT), for children around the age of two years (chronologically);<sup>181</sup>
  - iii) the Autism Screening Questionnaire (ASQ), for children under the age of six years;<sup>28</sup> and,
  - iv) as an alternative to ASD-specific standardized screening tools, the primary care provider may systematically inquire about development of language, social abilities, joint attention skills, and pretend play. Sample questions are listed in Appendix 3.<sup>64,65,246</sup>

## § 5.4 Outcome Objectives and Indicators

### **Objective:**

All British Columbia children with ASD are identified at the earliest possible age.

### **Indicators:**

- proportion of children subsequently shown to have an ASD that received some form of **general developmental surveillance** in the primary care setting;
- proportion of children subsequently shown to have an ASD that received some form of **selective ASD screening** in the primary care setting; and,
- proportion of children subsequently shown to have an ASD that were first identified based on:
  - parent concern;
  - other caregiver concern; and,
  - as part of routine preventive developmental surveillance (asymptomatic).

### **Target:**

Primary care providers identify children subsequently shown to have an ASD as being at high-risk within three months of first voiced parent/caregiver concern, or of first clinically manifested symptom.